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ABSTRACT

This monograph presents four reports on the care of children with disabilities, resulting from a study/travel project in Greece, Turkey, Egypt, Kenya, South Africa, Seychelles, India, Nepal, Thailand, Singapore, and Indonesia. The first report focuses on the medical, educational, and social care of children with disabilities. It first summarizes the status of rehabilitation efforts overall and then provides a summary of rehabilitation efforts by individual countries visited. The social circumstances of children and their families are reviewed and major problems identified. The second report focuses on innovative ideas in rehabilitation seen during the trip. These address: collecting data on disability, changing societal attitudes, personnel development, health care delivery, technical aids, education, vocational training and income generation, family support, and service delivery. Community-based rehabilitation is the focus of many of these innovations. The third report is on pioneering effective solutions in rehabilitation. Topics covered include: promoting a national network of knowledgeable, skilled organizations; establishing a health care infrastructure; providing affordable technical aids; increasing social acceptance of disability; changing awareness of the potential for improvement; demonstrating a model for integrated education in urban and rural settings; and increasing levels of education. The fourth report looks at societal attitudes and the disability movement, focusing on ways people with disabilities are viewed; ways availability of services has improved; personnel training and professional standards; roles of families, schools, churches, and community organizations; how people with disabilities influence change; response to needs and resources of families; and how disability advocates can help in other countries. Contains 38 references. (DB)

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[Care and Rehabilitation of Children with Disabilities around the World]
1992 IEEIR Fellowship Study

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International Exchange of Experts and Information in Rehabilitation

IEEIR

1992 IEEIR Fellowship Study

Medical, Educational and Social Care of Children with Disability: Mediterranean, Africa, India and Southeast Asia

Report Submitted by:

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This investigation was supported (in part) by a fellowship from the World Rehabilitation Fund through the University of New Hampshire under a grant from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education Grant. #H133D00001

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WORLD REHABILITATION FUND, INC. AND THE UNIVERSITY OF NEW HAMPSHIRE
INTERNATIONAL EXCHANGE OF EXPERTS AND INFORMATION IN REHABILITATION

Medical, Educational and Social Care of Children with Disablility
Mediterranean, Africa, India and Southeast Asia

A Study Done in 1991-1992

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December 1992

This investigation was supported (in part) by a fellowship from the World Rehabilitation Fund, under a grant from the National Institute of Disability and Rehabilitation Research, U.S. Department of Education, Washington, D.C. 20202-2646, Grant #H133D00001 and (in part) by a grant from the Rainier Foundation, Seattle, Washington

Medical, Educational and Social Care of Children with Disability

Mediterranean, Africa, India and Southeast Asia

In every country, acceptance of disability improved during recent years. Many people attribute this change to the multiple activities spawned by the Decade of Disabled Children declared in 1980 by the World Health Organization. Member states of WHO agreed to include rehabilitation in their health goals by the year 2000. Governments were encouraged to consider the civil rights of disabled people. Discussion and, in a few cases, adoption of public policy or laws regarding education, jobs and environmental access occurred. There has been general acceptance of the principals of normalization and integration, at least at the level of policy statements. Information about disability and about services appeared in public media raising the expectations of both parents and professionals. They learned that through treatment and education, these children, generally regarded as "useless", could become "useful" citizens. The result has been an increasing flood of requests for services, especially from educated, urban families.

STUDY/TRAVEL PROJECT

The information to be presented herein is not carefully researched, nor is it a representative sample of opinion. Rather, it reflects information gleaned in interviews and discussions with over 100 leading professionals, perusal of disability newsletters and reports, and from visits to 80 programs or government offices in 11 countries during a ten-month period. As a Fellow of the International Exchange of Experts and Information in Rehabilitation, I traveled in 1991-1992 to study the care of disabled children in Greece, Turkey, Egypt, Kenya, South Africa, Seychelles, India, Nepal, Thailand, Singapore and Indonesia.

STATUS OF REHABILITATION EFFORTS

These countries are in various stages of developing rehabilitation programs. Primary attention focuses on preventive efforts and marshaling resources to provide intervention for as many children as possible. Little attention has been given to collection of information, either about incidence and prevalence of disability or about the effectiveness of treatment programs.

Data Based Information. The few statistics available are, in no case, current or reliable. Greece is the only country with a possibility of good statistics in the near future. A study to collect national data on prevalence of disability, current services available and additional services needed is being supported by the government.

Prevention. Health care priorities appropriately put preventive efforts in first place. All the countries are pursuing immunization, rehydration and nutrition programs. There is some education about improved birth practices (e.g., resuscitation, sterile cord care) and other traditional baby care practices. Almost no attention is given to education about genetic causes of disability or problems related to teenage pregnancy.

Intervention and Disability Management. Though the magnitude of services has grown and governments are lending support, both money and trained personnel to implement programs are grossly inadequate. The number of children needing services in each country who get them is minuscule. Only guesstimates can inform us about this percentage thought to be 5% or less overall except in Seychelles, a small country with extensive

foreign aid. The treatment centers and/or special schools are disability-specific, i.e., serving children who are either blind, deaf, physically (i.e., polio) or mentally handicapped. Children with cerebral palsy form a separate group. Severely disabled children are generally excluded. Comparatively, children with mental disability receive less attention than those with other types of disability, but this is beginning to change. Early intervention is not common. Low-cost, durable, artificial limbs are being developed in each country, but not nearly enough are produced for those who need them. Availability of wheelchairs is even more limited. The production of braces, crutches, special shoes, Braille materials and hearing aids is also limited. Glasses are more readily available.

Evaluation. Only in Greece, India and South Africa has rehabilitation reached the stage of evaluating the effectiveness of intervention efforts. A few of their funding agencies, programs or professional societies are concerned with critical appraisal of programs.

Service Delivery. Most programs for children with disabling conditions are provided by non-governmental organizations (NGO's) funded either externally by foreign donors or internally by charitable groups. With governmental entry into rehabilitation, a partnership has been developed with NGO's in which governments expect the NGO's to continue responsibility for programs with the aid of limited government funding. There are, in addition, some institutions and hospitals solely funded by government and others that have no government involvement. Considering the magnitude of the problem, NGO's must take the initiative to establish a network of rehabilitation services and collaborate with the government sector to use limited resources to an optimum extent.

The service delivery model has been center-based and often as residential institutions. These treatment programs and/or special schools were concentrated in urban areas. More recently, a community-based rehabilitation model has been viewed as a cost-efficient alternative to rehabilitation institutions while, at the same time, providing substantially greater coverage of the population, the majority of which still live in rural areas. Outreach programs from the institutions as well as community-based programs are appearing, especially in India and Indonesia.

There are also dual levels of health and educational services based on socio-economic status. Affluent people, including the large number of expatriates who work in these countries, use the private health care and school system that provides almost nothing for children with disabilities. Private schools, in particular, are elitist; any child with special needs will not be accepted. Special educators or therapists for private therapy or tutoring are seldom available. These families often seek help abroad. The lower classes are dependent on limited government services.

MEDICAL TREATMENT AND EDUCATION

Most rehabilitation is through programs founded by charitable organizations. Usually, they began with medical care and, subsequently, added educational and/or vocational components. Few hospital systems are organized for rehabilitation; some of the institutions have a primary, if not exclusive, focus on nursing care.

Qualities and type of medical services vary enormously among and within the countries studied. In Singapore and Thailand, in South African hospitals for white people and in some private hospitals in India, the standard of care is high. Well-trained physicians are practicing in modern facilities

with current technology and medical procedures. In contrast, abysmal conditions exist in many government hospitals in most countries due to lack of funding and personnel and the infrastructure being overwhelmed by the sheer number of patients. Traditional medicine (i.e., herbal treatments and massage) and spiritual healing continues to be a factor in health care generally.

Education is theoretically available in integrated special classes in government-funded schools everywhere. In actuality, admittance is dependent on the goodwill of overcrowded and understaffed schools. Moreover, children who cannot participate successfully without special consideration are expelled. Special classes in regular schools have appeared in limited numbers. These classes, too, are overcrowded and lack trained teachers or adequate materials written in the local language.

Medical schools, in all but Seychelles, train physicians as specialists in orthopedics, neurology and pediatrics. India produces a surfeit of doctors. , A few such sub specialists are practicing in most of the countries. Many medical schools also have physical therapy training, but the numbers graduated annually are extremely small. Occupational and speech therapy training is scarce.

Special education teacher training is new. The teachers are general educators often placed in teaching assignments without having experience or even an interest in special education. In Greece, Turkey, South Africa, India and Indonesia, college level training is offered in at least one university usually leading to a diploma rather than a degree. In the absence of formal training, some programs have developed a curriculum to train their own teachers. There is no expertise about specific learning disabilities or behavior disorders.

Costs must be borne by families. Health insurance is available only through employment in multinational corporations (and, in India, through government employment). Technical aids are never covered. Free government hospitals theoretically serve the poor, but practically cannot provide for the numbers of people. Government schools, too, are inadequate for the population and often have charges beyond tuition.

SUMMARY OF REHABILITATION EFFORTS

Greece. Three children's hospitals provide medical care for children with disabling conditions and high-risk follow-up is available from three neonatal intensive care units. When therapy is recommended, children are referred to one of the several half-day non-profits or full-day private programs. If no family member can be home to care for the child, a full-day, rather than half-day, program will be approved and families can use their government pension toward the fees. Physicians; physical, occupational and speech therapists; and special educators comprise the multidisciplinary teams in these centers and serve children from infancy to about age 16. The government runs the only residential center for children who are mostly from villages where service is not available; there is no educational component. Approximately 90% of the children in the urban areas on the mainland are thought to receive services, but few in the countryside and in the islands do so.

Turkey. Turkey is serving 3-5% of its children. The state supports nine boarding schools for those who are blind, 35 for hearing impaired, and two for those with orthopedic disabilities. In addition, there is a charitably funded Spastics Society program in Istanbul. The state also pays for needed surgeries

and technical aids for students in these programs. There are no pediatric sub specialists or speech therapists in the country. However, phoniatricians (physicians) treat people with hearing problems. Occupational therapists are rare and none serve children. Physical therapists are scarce.

Egypt. The most extreme paucity of services and trained personnel exists here. All programs are quite small and charitably funded. In Cairo, there are only five programs for children with mental and/or multiple disabilities and a few more in Alexandria and Menia.

Kenya. Foreign aid has established many programs here; 82 institutions house 75-100 children each. The Association for the Physically Handicapped runs a Children's Orthopedic Clinic with a mobile clinic in five towns. They arrange sponsorship for surgeries and technical aids.

South Africa. Here there is a strong dual system. One serves white people with a variety of excellent programs that are both charitably and government funded. Most children get services from well-trained professionals of all disciplines. In contrast, fewer than 1% of children of color get anything. For example, there is one physical therapist for 300,000 people in the black townships around Cape Town. Residential institutions are big in South Africa; 1,500 is the average number of people on one campus. Children and adults with mental disability and cerebral palsy are housed in a separate compound, but are placed in the same institutions for those with mental illness or tuberculosis.

Seychelles. This small country has a hospital with a therapy department, eight clinics on the three largest islands that provide P.T., O.T. and speech therapy, a School for Exceptional Children, and a Rehabilitation Center. All programs are staffed by expatriates on contracts. Most children are served.

India. India has a large number of charitable programs as well as public that are estimated to serve about 3% of children. There are some excellent programs with well-trained professionals, including neonatal intensive care and high-risk follow-up. The government and foreign donor organizations have made a rather strong commitment to community-based rehabilitation and are implementing this in various projects. Some of the finest examples of low-cost technical aids using local materials are found here.

Nepal. Next to Egypt, Nepal had the least services available reaching less than 1% of children in 46 small programs. All are run by foreign, charitable donors and located in the two urban centers of the country. Hearing impairment is a major problem. Two audiologists recently opened a speech and hearing clinic at the university hospital. Two physicians at the small Hospital for Disabled Children perform orthopedic and cleft lip and palate surgeries. The few physical therapists there were trained by foreign volunteers.

Thailand. Despite the prosperity of this country, fewer than 5% of children attend programs. There are three government-run institutions each for children who are blind or mentally disabled and nine for children who are deaf. Charitable organizations also maintain three institutions for children who are blind and one each for those who are mentally or physically disabled. There is a Medical Rehabilitation Resource Center funded by Save the Children and large rehabilitation programs in several hospitals. There are, however, no outreach programs from these urban centers and only two community-based rehabilitation programs being attempted.

Singapore. Singapore is also relatively wealthy. Nevertheless, only about 5% of children attend programs in this city-state. The National

University Hospital has the only Pediatric Rehabilitation Clinic offering multidisciplinary care and developmental assessment. There are three day programs for children with multiple disabilities; seven for those with mental disability; two, with hearing impairment; and one, with visual impairment.

Indonesia. Indonesia has about 200 programs serving an unknown percentage of children. Though some are government sponsored, most are operated by charitable organizations and located on the main island of Java. The government has adopted the philosophy of community-based rehabilitation and set up an infrastructure to expand it.

SOCIAL CIRCUMSTANCES OF CHILDREN AND THEIR FAMILIES

Despite increasing societal awareness and acceptance of disability, the social circumstances of disabled children and their families have changed little except among the educated and affluent. Commonly, such children and their families experience pity and shame, and they are frequently ostracized. The stigma of disability attaches to their siblings, disqualifying them from marriage. This leads to an attempt at a hidden existence from neighbors and friends. In Greece, this is true to the extent that some families forego government pensions to which they are entitled for their child's care. Even in educated families, the desire to "get rid of" such a child remains, and there is great demand for residential institutions. Relatively few institutions exist, however, so families reluctantly keep them at home.

In spite of disability being a great burden, socially and economically, families do care for the children. Abandonment is rare and negligence seems limited to dire situations in which extended family is not available to help. In Kenya and Seychelles where taboos exist only in regard to epilepsy and mental illness, children with physical disabilities are not shunned but often become a pet of the family. Belief in karma plays a significant part in acceptance of disability and willingness to seek treatment. In Buddhist and Hindu cultures, a person with a disability is believed to be suffering in this life for bad deeds committed in a former life. This belief is particularly strong in Nepal and India and may be responsible for the occasional severe neglect reported to occur.

Exclusion from community life for medical treatment, education and work is the norm. As we have seen, programs segregate people with disability into separate settings.

Social services to assist children or their families hardly exist. Support for parents such as counseling or parent groups are unknown outside Greece and South Africa. School transportation is available in a very few programs in Greece, South Africa, India and Singapore. Singapore also has taxi subsidies and provides the only respite care.

Taking the broadest definition for "social services," the following summarizes what else is happening in the countries investigated. (1) The Greek government has a national program of visiting nurses that provides some family support. Seychelles, too, has maternal-child health nurses that visit new mothers monthly and follow high-risk babies. (2) Thailand passed a Disability Rights Act last year that insures education, medical rehabilitation, access to buildings and quotas for disabled workers. Turkey, also, has recent legislation that set quotas for businesses to employ disabled workers and established regional guidance and research centers to assess disabled children for school placement. Legal recourse is not included in either country's legislation. (3) South Africa has a Child Welfare program to investigate abuse and neglect, and there are government grants to assist families financially.

The amount varies according to the child's race with children of color receiving significantly smaller amounts than white children. Seychelles and Kenya also provide a monthly stipend. The latter has financial assistance for housing shared with another disabled person. (4) Singapore has income tax relief for families and respite care for a few days or weeks with a signed parental commitment to return for the child. (5) India has had a number of schemes available in different states: seed money to start a small business, old age homes, monthly financial assistance, subsidized artificial limbs and tricycles, scholarships and petrol subsidies. Many are no longer available due to budgetary limitations.

MAJOR PROBLEMS FACED BY CHILDREN AND FAMILIES

With few exceptions, the same problems were cited in every country:

- Lack of family awareness of the benefit and availability of services.
- Family unwillingness to seek services because of societal taboos or belief in karma
- Insufficient medical and educational services
- Lack of ability to pay for services
- Lack of trained professionals
- Lack of employment opportunities

SUMMARY

Throughout my travels, I found dedicated people committed to working with children who are growing up with disability. They do so in the face of enormous challenges and conditions of severe, widespread and growing shortages of housing, education, health care and employment. Nevertheless, societal attitudes and government policies are changing to accept and help. There are vast resources and skills in some of these countries, notably India, where a great deal of work, research and development has already occurred. It is critically important to build a worldwide network for dissemination of information about the services that promote optimal outcomes for children and to provide encouragement and support for all those involved in rehabilitation.

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INNOVATIVE IDEAS IN REHABILITATION

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INNOVATIVE IDEAS IN REHABILITATION

Mediterranean, Africa, India and Southeast Asia

Charlene Butler, Ed.D.

There is a vast, but largely untapped, resource of information and skills in developing countries. Most programs work in isolation unaware of other individuals or organizations who may be carrying out similar work and without regional, national and international forums to disseminate ideas. In 1991-1992, I traveled for ten months through 11 countries to look for innovative ideas in the care of children with disabilities. In 80 site visits, I met with over 100 leading physicians, therapists, educators and administrative officials in Greece, Turkey, Egypt, Kenya, South Africa, Seychelles, India, Nepal, Thailand, Singapore and Indonesia.

Though the services have been limited, rehabilitation has a long history in many countries. Most programs were founded and are operated by voluntary organizations funded by external (foreign) donors or by internal charities. The primary service delivery model continues to be an institutionally based one. Commonly, these are separate treatment and/or school programs for a particular type of disability (i.e., blindness, hearing impairment, mental or physical disability). Such a model has major drawbacks. Fewer than 5% of disabled children in each country have access to the services. They have a high cost and require specialized staff for which there is insufficient personnel. The target groups are isolated in residential programs--a setting that does not prepare them for successful reintegration into village or urban life after "rehabilitation". Special day programs present the problem of transportation; it is expensive, crowded and inadequate. In addition, taboos against disability make some families reluctant to bring children out to day treatment programs.

More recently, community-based rehabilitation has been viewed as a cost-efficient alternative to institutionalized services while providing substantially more coverage of the population. The goals of community-based rehabilitation are practical and functional: (1) to be able to look after yourself, (2) move around your house and village, (3) carry out household activities, (4) enjoy family life, (5) take part in community activities, (6) attend school and (7) do meaningful work.

For many years, international organizations from Western nations have given money, equipment and technical assistance to establish or support rehabilitation programs. Unfortunately, "outsiders" often brought, with their money and expertise, their own ideas about the needs and solutions for rehabilitation programs. The rejection rate was high though quiet; programs simply dried up when they left. It became clear that ideology and technology transfer cannot flow, unmodified, from developed to developing countries. Instead, programs, procedures and technical aids that conform to sociocultural practices are needed-- that are also based on established scientific principles and accepted concepts of normalization and integration. In other cases, money and equipment was misappropriated, never reaching those for whom it was intended.

Culturally appropriate and practical solutions in designs, materials, techniques and programs are now evolving in these countries. Such solutions have more direct application for other developing countries that share similar problems. They must change societal attitudes about disability. They must extend services to large numbers of people who are, as yet, unserved in any

way. They must train professionals with low levels of education to be generalists rather than specialists providing 1:1 service. They must reach scattered people with cost-effective methods they can afford and simple technology they can produce and maintain.

To those of us in the West, there is an indirect effect on our own approach to rehabilitation that comes from examining solutions in developing countries. "Exposing the unexamined assumptions of our society to an alien setting gives us a chance to look at and evaluate those assumptions from a different perspective." (Frank Herbert, author of DUNE) New perspectives may lead to changes at home and in the way in which we provide assistance to others.

Following is a capsulation of good ideas observed in my travels that may be helpful to others. Written information and/or reports are available by writing to the people who are referenced.

ESTABLISHING DATA ON DISABILITY

In Greece, the Ministry of Health and Education is cooperating with physicians to conduct a comprehensive, two-part survey to determine the prevalence of disability in the country and the current level of all services.[1] There are two extensive survey forms that will be completed in door-to-door interviews. The Disabled Find Project will document prevalence, distribution and types of disabilities. The Documentation of Services Project will describe current services and percentage of population having access to them versus those who receive no services. Both the content and logistics of data collection will provide a model for other countries, few of which have any data to aid national policy or intervention planning.

The Maryknoll Catholic Mission in Nepal[2] carried out a survey in the difficult geography of mountain villages in the Himalayas that are accessible only by foot. This study to determine prevalence of mental retardation was conducted through personal interviews.

CHANGING SOCIETAL ATTITUDES

Peoples Awareness of Disability[3] is changing attitudes in South Africa through education of school students. This multi-racial group presents a two-hour program that includes simulation activities and opportunity for questions and dialogue with adults who have a disability. Over 60,000 students, ages 6-18, have attended one of their programs. PADI started its work in Johannesburg, has spread to the Cape and has just trained its first team to go into a rural area. In addition, they have expanded their educational activity to reach doctors, therapists, teachers and psychologists in training as well as people who work in the travel industry.

Street plays are used by the Sourabha Community Based Rehabilitation Program in India.[4] They are an effective method for reaching villagers and people who live in urban slums where other types of media seldom penetrate. Simple scripts about disability issues are enacted for the entertainment and education of a whole village or slum area which will turn out for such an event.

An incredible ten-year effort in Thailand has culminated in the Rehabilitation Act. This national legislation provides equal opportunity for education and jobs, environmental access, and government-paid medical care and technical aids. The Council for Disabled Persons[5] implemented a formal organization of people with disabilities to work for full participation under the

law. They have achieved this important initiative through getting recognition and acceptance by the government and private organizations as the representative of disabled people and lobbied successfully to be included in their decision-making process. Now the task is to educate people across the country about their rights and to register themselves with the Department of Public Welfare. Strategies to be employed include a newsletter and mass media notification about why people need to register, i.e., (1) to establish a national data-base on prevalence of disability and (2) to be identified for services.

Classical dance continues to be important in Indian cultures. Expectations are being raised about the abilities of people who are blind through the classical dance program at the Shree Ramana Maharishi Academy for the Blind in Bangalore.[6] National recognition has come to one young man for his outstanding performances.

"It's Difficult with Only One Leg but It Can Be Done"[7] is the title of a video documenting a special 6-day course by Outward Bound. Outward Bound is an organization founded in Scotland which has extended to many countries, including Indonesia. It is a course in character development by means of physically challenging activities (i.e., rock climbing, hiking, camping, canoeing, and rope work) and problem-solving exercises. The participants discuss, at regular intervals, their reactions to the challenges and how they went about meeting and overcoming the problems. A special six-day course was arranged for the staff of Pusat Rehabilitasi YAKKUM, 18 of whom were disabled. The course was not changed except to allow more time to complete the various challenges. Several participants were amputees, some had paralyzed limbs and used braces and one used a wheelchair. This video and other media coverage provide examples of capabilities that can help increase societal expectations.

An annual national concert and special art exhibition brings the work of musicians and artists who have disabilities to public attention. The Singapore Council of Social Service[8] sponsors these programs.

Another idea from the Singapore Council of Social Service[8] solves the need for transportation and the need for positive interaction between those who are and who are not disabled. CareCab Club is a project that assists people who have trouble using public transportation because of a disability. A person who needs a daily transportation arrangement to work or to school is matched with a volunteer taxi driver. The membership in CareCab Club has grown to 255 drivers and 247 people with a disability. This buddy system is brought to the public's attention through a media tribute paid to the drivers.

PERSONNEL TRAINING

Ain Shams Centre for Rehabilitation[9] is the only program for children with physical and multiple disabilities in Egypt. Out of necessity, the director developed a curriculum to train teachers for this population. Lecturers from the local universities join the Director the two staff physicians to teach the two-year basic and two-year advanced courses. It is an on-the-job course of study intended for people with an equivalent of eighth grade education. They have graduated about 80 teachers.

Imaizan Yethu Project[10], in South Africa is a special education program in a black township needing to train teachers who begin with a very limited educational background. They are using mothers of disabled children working in teams of two for each class. The curriculum had not yet been committed to a written form, but I saw excellent examples and ideas being used

to communicate essential concepts about how to manage groups of children with special needs and learning problems.

The Kenya Institute of Special Education,[11] with funding and technical assistance from the Danish International Development Corporation, has developed a correspondence course curriculum. This extends training opportunities off-site to reach more potential teachers.

Insufficient personnel are a major problem in all these countries. Physical therapists, in particular, are in short supply. A thorough, though very technical, manual (CARE IN OUR HANDS), provides the standard informational content for physical therapy assistant certification in South Africa[12]. It covers all systems of the body (e.g., musculoskeletal system), medical conditions (i.e., cerebral palsy, strokes, mental retardation, rheumatism, head injury, amputations, chronic respiration, fractures), and treatments (i.e., re-education of walking and walking aids, massage, electrotherapy, exercise). Educational prerequisites include at least a high school degree for this training that is preparatory for hospital employment.

One of the most outstanding examples of innovative work anywhere is COMMUNITY-BASED REHABILITATION WORKERS.[13] In South Africa, a physical therapist created a training program to meet the overwhelming need for health care in the area's black townships and squatter camps. The only P.T. for 300,000 people, she saw her task to be passing on basic rehabilitation skills to empower the community to take responsibility for health and decrease dependency on the too-few medical experts. The training program is an intensive four-week course taught in the language of the local area. The only prerequisite is to be able to read and write. The excellent manual contains the course content and suggestions for teaching including how to incorporate traditional beliefs. Explanations of diagnoses and treatment are simple, yet capture fundamental concepts that enable understanding of complex ideas. Attractive drawings help illustrate the concepts which are presented in a larger context that the rehabilitation task is to facilitate as normal development as possible in a loving, caring environment. Sections include general health (i.e., handicap, nutrition, breast feeding, oral rehydration and immunization), normal functions (i.e., skeleton and movement, and normal development), conditions and treatment (i.e., cerebral palsy, Down's Syndrome, mental handicap, hydrocephalus, spina bifida, polio, blindness, deafness, stroke, spinal cord injury and amputations) and patient management (i.e., contractures, fits, pressure sores, urine and bowel management, chest infections, feeding children with cerebral palsy, toy making, welfare assistance, and assessment and recording). Though this was designed to train rehabilitation workers with very minimal education in severely disadvantaged settings, the content has wide application. Paraprofessionals who work as teaching-, therapy- or nursing-assistants, regular classroom teachers, volunteers, parents and family members could all benefit from the cogent explanations. Health care professionals will find it a model for conveying information without medical jargon.

HEALTH CARE DELIVERY

Traditional cultural practices have a great influence on current morbidity and mortality in developing countries. Many practices are good ones that appear to be based on common sense, logic and scientific justification. Some, however, have undergone change over decades, becoming unacceptable. The use of home remedies, being cheap and readily available, is a vital issue as there can be a thin line between usefulness and quackery.

Western medicine has made little attempt to integrate its science with traditional medicine. In India, a keen desire to retain the rich traditions of neonatal care without perpetuating superstition and harmful practices led to a study by the National Neonatology Forum. It reviewed the literature and collected current data about prevalent practices and related beliefs from different parts of the country and different strata of society. These were examined by experienced practitioners from western and various systems of traditional medicine to arrive at common recommendations that should incorporated in the training of community health workers and birth attendants. The utility or futility of commonly used home remedies and commercial preparations were also studied. Origin, description, objections and recommendations for each practice are given. Practices covered include cord care, resuscitation, pre lacteal feeds, colostum and breast feeding, wet nursing, nose and ear piercing, baby bath at birth, etc. The recommendations relate to (1) beneficial aspects of the practice that should be promoted, (2) harmful ones that should be discontinued, (3) innocuous practices that may be continued and (4) practices about which further research is needed. Details of this national study are found in the excellent book, TRADITIONAL PRACTICES OF NEONATAL CARE IN INDIA. [14] It also contains short chapters reviewing the literature of traditional practices in Southeast Asia, principles of care in traditional medicine systems and western medicine and use of home and over-the-counter remedies. This book deserves wide readership both in India and, as a model, in other countries where similar studies should be made. Such studies could also address tribal and religious customs that relate to baby care.

Children who have difficulty sucking or swallowing may be fed more easily with a palada than with a spoon.[15] This small steel or aluminum cup with an elongated lip/spout was used in Indian villages for baby feeds and medicines before bottles were introduced. Because of its shape, mothers find it more convenient to hold and feed the child larger quantities without spilling and with little risk of aspiration.

Follow-up after surgery is a challenge when children come from distant and isolated mountain villages. The Hospital for Disabled Children [16] in Katmandu addresses surgically correctable orthopedic problems of such children. They have trained field workers to follow-up in villages, organize mobility camps, locate lost patients, and link them to other organizations.

General health service delivery to rural areas in the island nation of Indonesia is difficult.[17] Thirty Mobile Rehabilitation Units have been established in 27 provinces. Each unit consists of professionals who spend an average of two weeks per year in each village. Their objectives are to increase public knowledge, educate parents, assess and check children, provide technical aids and make referrals for medical treatment in hospitals. To serve remote Irian Jaya, a floating boat-based general health clinic calls at villages on the sea and up navigable rivers.[18]

TECHNICAL AIDS

Standard manual wheelchairs are not functional in areas without sidewalks or paved streets and where roads are teeming with dangerous, unregulated traffic. The Kepha Motorized Wheelchair [19] has solved that problem for its designer who is dependent on wheels. He is now commercially producing it for others. Looking nothing like a wheelchair, this three-wheeled vehicle has with large tires and a gasoline engine. It is highly functional and can go most anywhere, even when heavy rains render roads

difficult. Many people in developed and developing countries could use this design.

A physician at the Kasturba Medical College[20] is also grappling with the need for technical aids. He has both a technical and a funding idea. Artificial limbs need to be durable and affordable, but also well designed for comfort, function and appearance. The Jaipur foot, developed in India, has become the standard artificial foot in countries where most people go barefoot or wear sandals. Its design allows movement that is more functional than a prosthesis designed for a shoe and allows cheap and easy production using readily available materials in developing countries. Using the Jaipur foot, a below-the-knee artificial leg with the same attributes as the Jaipur foot has been developed and is being tested for durability. Though the cost is projected to be only about $30 U.S., this is a princely sum for most people who must pay for limbs themselves. A fund has been set up to which contributions are made; interest that accures on the fund will be used to subsidize the cost of the artificial limbs for those who need financial assistance. The unusual aspect of this fund is that donors will be allowed to withdraw their money if they should ever wish to do so.

An Innovative Poster Section was a part of the National Neonatology Forum XI Annual Meeting in India.[15] An opinion poll selected the "best idea"; there was a tie between "Solar Energy for Care of Newborn Babies" and "Warmer Cradle As Alternative to Incubators for Thermoregulation in Neonates". Substitution of solar for electrical heat was successfully used to provide warmth for very low-birthweight babies in the former. In the latter, a wooden drawer with three rows of 25 watt bulbs was attached to the bottom of a regular metal cradle. The base of the cradle had small perforations. A heat-shield was used to cover the babies in the cradle. It was very inexpensive and could be easily cleaned and fumigated. Other interesting innovations reported included the use of an empty I.V. fluid bottle for neonatal resuscitation, a simple device to warm and humidify oxygen, a simple device for urine collection in newborns, treatment of inverted nipples in mothers using a disposable syringe, and a training program for neonatal resuscitation.

Sample surveys suggest that about 17% of the people in Nepal have a significant hearing loss. The new Speech and Hearing Clinic at Tribuhaven University Teaching Hospital[21] has developed some excellent teaching materials to educate villagers about prevention and treatment of hearing impairment.

A non-profit company[22] is working with the Tribuhaven University Speech and Hearing Clinic to solve a problem in providing hearing aids. Earmold impressions can be made in remote areas and transported for production to a lab in Katmandu, but transportation of these impressions without distortion, has been difficult. A new material, imported from the United States, has solved this problem.

EDUCATION

Nepal has adopted a National Special Education Plan.[23] Education for all in integrated settings is the main thrust of the plan developed in a cooperative effort between Westerners and Nepalese service providers. This is a comprehensive plan which seeks to serve remote villages as well as urban areas and to coordinate the efforts of government and non-governmental organizations to deliver educational services.

Integrated schooling is an accepted principle everywhere, at the level of policy statements. In reality, it hardly exists. Amar Jyoti Research and

Rehabilitation Center[24], however, is an exception. In their school, 50% of the children have polio and 50% are non-disabled. They have overcome taboos that ordinarily preclude association with disabled children by providing free schooling to children who live near the school. This is a very strong incentive.

The Education Center for the Blind is demonstrating that integrated education is feasible in non-urban Thailand. For integrated education to be successful, children must be independent in learning and self-help and (2) regular classroom teachers and classmates must accept them. A special class has been set up for children who are blind. They attend for one year of intensive training in Braille, mobility and independence in daily living skills (i.e., eating, dressing, toileting). Afterward, they transfer into a regular class in their home village. The receiving teacher attends a brief training before the child begins. The teacher learns about disability and is, hopefully, more accepting of the child and prepared to help other children accept the child. Some 80 teachers have been trained.

Strictly oral programs, rather than sign language and/or total communication, are the standard in deaf education in these countries. I saw one exception; the Naxal School for the Deaf changed two years ago to total communication.[26] They are using the sign language manual that was recently developed at the Speech and Hearing Clinic. As with many programs, they must train their own teachers and have developed a curriculum to do so. It may be useful to other programs interested in adopting the philosophy of total communication.

The Thai Sign Language Dictionary[27] is the only other effort I saw to make sign language available. In this case, the community of deaf people codified their sign own language. The manual is uniquely organized by similar hand movements.

Moving students from residential special schools back into the community is seldom addressed. At Yayasan Pendidikan Dwituna[28] , though, two older students live in a rented house near the school to learn to live in the community independently. They get support from each other and from school staff as needed until each is ready to return to their home village or town.

Another good idea seen at Yayasan Pendidikan Dwituna [28] is their preschool intervention program for children from distant villages. A mother and child come and spend two days working intensively with a teacher and a mobility instructor. They live at the school and return periodically for new information, activities and toys for their children.

A common need is for program and learning materials in local languages. The Portage Project is a home-based preschool intervention program that is widely used. The Ain Shams Rehabilitation Centre[9] developed an Arabic version and is pilot-testing it.

A superior early childhood intervention program for parental use has been developed by an interdisciplinary group in India and tested in seven centers for children with developmental delays (birth to two years of age).[29] This program is relevant and understandable to parents because it focuses on self-help tasks. Each task has been analyzed for prerequisite skills. The 250 measurable skills are also grouped sequentially in four areas of development (motor, language, cognitive and social). For example, self-help task #18 is Feeds Self with Fingers. To do this, one motor skill (Uses Pincer Grasp to Pick Up Object), two cognitive skills (Individually Takes Objects Out of a Container and Performs Simple Gesture on Request, i.e., Clapping Hands) and two language skills (Points in Response to Simple Questions and Articulates Using Sounds to Indicate Preferred Objects or Needs) must be present. Activities and

materials to develop the individual skills are specified. UPANAYAN, A Programme for the Developmental Training of Mentally Retarded Children (0-2 Years) is available in English in a written manual or as computer software (IBM compatible). It is being translated into a number of Indian languages.

VOCATIONAL TRAINING AND INCOME GENERATION

Employment of disabled people is one of the most pressing problems in all nations. Some of the most beneficial solutions are those in which the employment helps other disabled people. In Kenya, disabled people produce modest walking aids at an affordable cost; in the Occupied Territories they make toys for developmental preschools and in South Africa they teach school students about disability. Another important principle in employment schemes was being pursued in Kenya, i.e., jobs that have a high visibility in the community and present disabled people positively as contributors to the society. For example, bakery workers or sellers of self-grown produce or flowers are important members of a community.

At the School for Orthopedically Disabled in Turkey,[30] there was a strong program in pattern-making and tailoring and in making Turkish carpets. (Students in the tailoring classes make all the school uniforms.) These are potentially profitable skills in this country and ones that can be practiced at home.

At Shree Ramana Maharishi Academy for the Blind in India,[4] vocational training begins at age 14 with students learning all aspects of the manufacture of cardboard boxes. Students are paid for the hours they work, and the money accumulates in a bank account for them to have at graduation. Vocational trainees at the Association for Physically Handicapped in India[31] get help to set up cottage industries. To deal with problems of transportation, the Association also acts as a middle man in one cottage industry by arranging for contracts with businesses to assemble electrical products. They deliver the parts to the homes of workers and collect the finished product.

A separate employment cooperative of 130 people has spun off from the vocational training program at Pusat Rehabilitasi YAKKUM.[7] High quality leather goods, carvings, lamb skin products, and soft and wooden toys are being produced and marketed abroad with a professional-looking brochure. Usually the work is done at home, but people may work together at the Center.

At the Thirumurthy Rural Development Centre, blind boys, ages 9-22, spend two years in a special village training program.[32] Here they learn skills that will have direct application on return to their own villages and allow them to be contributing members of their families and community. I saw boys at work busily preparing fields of rice, mulberry and fruit trees, shinnying up a palm tree to cut a ripe coconut, and caring for silk worms, poultry and dairy cows.

Instead of setting up special vocational training programs, the Sourbha Community-Based Rehabilitation Program is networking with existing programs.[4] In this case, the Rural Women's Self-Employment Training Institute agreed to accept women with disabilities into their program. Graduates qualify for loans from a bank upon graduation to set up collaborative cottage industries such as baking or sewing.

A United Nations Development Program in Indonesia[18] underwrites Disabled People's Business Groups. They have arranged a 50% bank guarantee for a business loan to a small group of people who start a business together.

FAMILY SUPPORT

A toy library for disabled children is an idea that originated in Sweden and has been implemented in other countries. Toys are expensive, however, and the capital expenditure for a library is beyond the reach of many organizations even in relatively affluent countries. An occupational therapist in Cape Town[33] solved that problem--making a toy library possible for the most disadvantaged communities and promoting recycling in the process. She has developed toys made from junk or thrown-away objects to stock a toy library. Parents come to the library where they learn about various toys from the therapist or volunteer. A card for each toy explains: (1) the toy name and suitable age range for its use, (2) how children play with it, (3) what they learn through playing with it, (4) things to say and do to help children use it and learn from it and (5) how to make it. The parents make the toy that is recommended or that they want from a box of "junk" materials provided at the library. They may keep it. Some of the toys I saw were the following: bottles and lids, threading cards, sock puppets, "telephone" cans connected with string, wire cars and a cardboard doll house. I also saw sturdy, brightly painted, child-sized chairs and tables made of thick cardboard. (Ideas for toys are available from the World Health Organization publication: WHO RHB/83.1, TRAINING DISABLED PEOPLE IN THE COMMUNITY, Section #27, pages 492-527.) An additional spin-off of their project was that families and neighbors began to conceive new toys which they, in turn, shared with the library.

Families whose children have spent years at a special residential school are often reluctant to have them return home out of lack of understanding about how to help them. A very successful re-entry program is working for children who are blind and/or have multiple disabilities.[28] Students are phased out of the residential program over a two-year period. The first term of the phase-out is full-time at school but with intensive focus on self-help and skills that will make the child a contributing member of the family. These include cooking, housecleaning, washing and making paper bags from newspapers that can be sold to produce income. In the second term, the child is at school for four-week periods and home for two-week periods. Teacher visits are made for home and community orientation instruction and for parent training. In the third term, children are at home for four weeks then school for two weeks; again the teacher makes home visits for support. By the fourth term, the children are at home full-time with weekly visits by the teacher. In the fifth term, the teacher makes a visit every two weeks, and in the final term, the teacher visits once a month.

SOS Villages for orphaned children is an idea from Germany in which family life is simulated. Each home in the village has 8-9 children with a "mother". An "Auntie" takes over when the mother has time off to care for her own family. There is a "father" who is in charge of the whole village. This culturally appropriate model is well conceived. In Nepal, there is an SOS Village for Disabled Children who are residential students at a special school.[34]

Families of disabled children everywhere share the worry about what will happen when their child grows up. How, where, can--they live independently of their family? The Director at the Harry Kessler Center, UCP Johannesburg is helping a group of parents tackle that problem by planning for their children's future.[35] They are establishing a group investment fund that will grow through the years. Their goal is to accumulate sufficient money to build a suitable group home when their children reach adulthood.

SERVICE DELIVERY

Government allocation of money for education and treatment of disabled children is often based on category of medical condition that is not a good measure of the amount of care or intervention that is needed for a particular child. A better measure is one that addresses severity of disability A simple, quick evaluation process and form is used at the Harry Kessler Center[35] which allows each child to be assessed on the basis of physical and mental frailty. Needs related to mobility, persona hygiene, nutrition and eating, dressing, vision, hearing, treatment (i.e., medication, bed sores), toileting, therapy, communication, emotional status, intellectual level and general orientation (i.e., to time, place, people) are considered and scored: A total score reflects level of care.

Interdisciplinary care is not a concept of care that is practiced in most of these countries. Treatment programs are not set up to facilitate it. Two programs have recently begun an interdisciplinary clinic that may be of interest to others. There is a neuromuscular clinic in Greece[1] and a pediatric rehabilitation unit in Singapore[36].

Currently, community-based rehabilitation (CBR) programs have been established in over 40 countries. They are primarily small scale rural projects funded by non-governmental organizations. Information about these programs is fragmented, and the people who run them have little time or expertise to evaluate their results. The CBR Development and Training Center in Indonesia[37] has many years of experience implementing community based rehabilitation programs. The Director recently received the Sasakawa Health Prize awarded by the World Health Organization for this work. Several approaches have been tried, including transit (short-term) special training villages, but the Center has become thoroughly committed to total CBR. This Center is now a collaborative partner with centers in Bangladesh, India and Canada to develop, evaluate and disseminate information about CBR.

ActionAid in India[38] is committed to extending rehabilitation services in a CBR model. A network of partnership is also being created to avoid duplication of services; to share expertise, experience and policies; to collaborate with government programs; and to evaluate coverage and effectiveness of programs. This is being done through the mechanisms of an annual symposium, establishment of a professional library, and distribution of an informative newsletter.

IN CONCLUSION

Information cannot be transported wholesale, but innovative ideas can be adapted. At the very least, they stimulate more creative thinking about solutions to our common problems. Sharing of experiences also links us around the world for mutual learning and encouragement.

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WORLD REHABILITATION FUND, INC. AND THE UNIVERSITY OF NEW HAMPSHIRE
INTERNATIONAL EXCHANGE OF EXPERTS AND INFORMATION IN REHABILITATION

Pioneering Effective Solutions in Rehabilitation

A Study Done in 1991-1992

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PIONEERING EFFECTIVE SOLUTIONS IN REHABILITATION

Charlene Butler, Ed.D.

Societies throughout the world are searching for ways to deal with some of the most difficult human challenges--food, housing, employment, health, education, transportation, the environment and disability. Ashoka: Innovators for the Public is a non-profit, U.S. organization committed to finding, supporting and linking "public service entrepreneurs" in developing countries. These are individual people who are introducing practical solutions to the difficulties facing their societies. Ashoka Fellowships nuture public service entrepreneurship in three important ways to produce tangible good for the people with whom they work directly and demostrate models through which the problem-solving capability of society, in general, can be increased. (1) They give economic freedom through a monetary grant to work full-time on an idea or project. (2) They provide recognition and access to important people whose help will increase the likihood of a successful outcome and extension of the work. (3) They link Fellows around the world with similar interests for mutual learning, encouragement and dissemination of information.

Public service entreprenuers operate within socioeconomic and political circumstances that facilitate or impede the spread of rehabilitation services. They may effect factors which promote the growth of rehabilitation such as: (1) the presence of a network of national institutions and voluntary organizations with adequate knowledge and skills, (2) an existing health and education infrastructure, (3) successful models that demonstrate the feasibility for extension of services and (4) the political will and social acceptance which values the need for such services.

Their work may be to overcome factors that impede. Among these are problems which include the following: (1) population explosion overwhelming existing services, (2) poverty directing family and community priorities toward daily survival, (3) low levels of education and/or illiteracy, (4) lack of awareness of programs available and/or their potential to improve the individual's or family's circumstances, (5) concentration of programs in urban areas whereas the majority of peope are scattered throughout rural areas, (6) lack of a cohesive group, i.e., vast differences within a country with regard to language, religion, socioeconomic status and culture, (7) lack of affordable, sturdy technical aids which can be easily repaired locally, (8) political instability, (9) political corruptibility and/or mismanagment, and (10) ongoing exodus of people from rural to urban centers creating urban slums and break-down of extended family.

For ten months during 1991-1992, I conducted a study-travel project, "Innovative Ideas in Educational, Medical and Social Care of Disabled Children in Greece, Turkey, Africa, India and Southeast Asia," as a Fellow of the International Exchange of Experts and Information in Rehabilitation. Ashoka asked me to scout for potential candidates for their leadership awards. Among the many competent and dedicated people with whom I came in contact during the course of this study, I was privileged to meet or learn about eight who, indeed, stood out. Following are brief summaries of those, whose work and vision, I felt might qualify and why.

PROMOTING A NATIONAL NETWORK OF KNOWLEDGABLE, SKILLED ORGANIZATIONS

Professor Hifzi Ozcan, a neurologist, is perhaps the "father" of the care of children with cerebral palsy and developmental disabilities in Turkey. He founded the Turkish Spastic Children's Society 20 years ago and has, through the years, assembled an interdisciplinary team at the Center in Instanbul in which resides most of the knowledge about cerebral palsy in the country. This small, nucleus group of therapists, teachers and physicians provides clinical service to about 2,000 children each year. Through his remarkable initiative, they have undertaken to extend that knowledge throughout the country. They have organized three National Congresses of Cerebral Palsy as well as the first conference for gym teachers to teach sports to the disabled. They are supporting, with a monthly in-service program, a branch of the Society which opened in another city last year and are planning to assist branches in another five or six cities which have requested help. A project for service delivery in rural areas lacks only funding for implementation. Dr. Ozcan has been in the forefront of changing societal attitudes about disability through the promotion of national games involving people with disabilities. His center organizes and directs Special Olympics; and this year, Dr. Ozcan has been appointed the National Director of the Turkish Sports Federation for the Disabled.

ESTABLISHING A HEALTH CARE INFRASTRUTURE

Dr. Elia Awwad has been tackling one of the problems of the people of the Occupied Territories of Israel who lack any governmental services or authority to organize or provide services. Palestinians in refugee camps, villages and towns have experienced a prolonged, violent military occupation with considerable death and disability. Dr. Awwad has brought together the few health care professionals who live there to form the Child and Family Consultation Center to identify mental health needs and to organize and coordinate efforts to alleviate the suffering of families, and especially children living under such violent circumstances. The Center, formed in August 1990, is working with existing organizations and ones forming in the future to plan a comprehensive community mental health service under the occupation which may be carried over into a period of national independence. Despite the lack of people trained in fields related to mental health in the Occupied Territories, they believe teachers, social workers and respected community organizers can, with proper training, have a substantial effect. Training programs have begun to learn how to diagnose , and in certain cases, intervene to help people suffering with psychological disorders.

PROVIDING AFFORDABLE TECHNICAL AIDS

Arabs outside the Occupied Territoritories in Israel have also been without any governmental services to provide for their social welfare needs. **Akram Ali Akkeh**, with other disabled colleagues, established the Arab Society for the Physically Handicapped in 1981 to provide a mobility aid to each member who pays a symbolic fee based on ability to pay. In the first year, over 400 devices were rented or sold. A second goal has been to provide employment. They have acquired a few sewing machines and are turning out attractive, well-constructed track suits and are generating income. Recently they organized a small conference to address the need for persons with

physical disabilities to have access to university education and to be involved in governmental planning and decision-making related to disability. They hope, in the future to have a workshop to manufacture and maintain wheelchairs with later expansion to bicycles and aluminum tubes. Eventually a center for mentally disabled and for the elderly, a sports programs and a hospital are envisioned.

Never able to walk because of polio, **Wycliff Kepha Anwanzwa** has relied on wheels all of his life. Wheelchairs, however, are not very functional in many areas of the world where sidewalks seldom exist, most roadsbeds are uneven terrain of dirt or rocks and paved roads are teeming with dangerous traffic. For himself, he engineered a motorized, 3-wheeled vehicle with large tires and gasoline engine that can go most anywhere, even when heavy rains render roads difficult. This was the only motorized vehicle I saw or heard about during my travels. At the request of others for such a device, he produced several more. Now he attempting to commerically produce the Kepha Motorized Wheelchair, currently employing one disabled and two non-disabled workers. Meanwhile, he works, as he has for some years, at the Orthopedic Workshop for the Association for Physically Disabled of Kenya which produces affordable braces, crutches and artificial legs. Mr. Anwanzwa's design could be used by many people in developed and developing nations.

Dr. Bhaskaranand Kumar is also grappling with the need for technical aids and is attempting to solve the problem on two fronts. He is concerned with the need for artificial limbs that are durable and affordable, but also well-designed for comfort, function and appearance. The Jaipur foot, developed by one of Dr. Kumar's countrymen, has become the state-of-the-art standard artificial foot used in countries where most people go barefoot or wear sandals. It's design allows movement that is more functional than a prosthesis designed for a shoe and allows cheap and easy production using readily available materials in developing countries. Dr. Kumar is filled with ideas and projects, but developing a below-the-knee artificial leg with the same attributes as the Jaipur foot is his overriding focus of endeavor because the need is so great. About 1,000 people per year need artificial limbs in his own state. With his colleagues in a Prosthetics Lab at Kasturba Medical Hospital, he has developed such a leg (incorporating the Jaipur foot) and is ready to test its durability.

Though the cost is projected to be only about $30 U.S., this is a princely sum for most people. Government funds which provided artificial limbs before 1987 are no longer available. Without insurance or government aid, few have the income to buy the artificial limbs they need. Hence, Dr. Kumar has also devised a creative funding plan. He has set up a fund to which people make donations. The ususual aspect of this fund is that donors will be allowed to withdraw their money if they should ever wish to do so. In the meanwhile, the interest that accrues will be used to subsidize the cost of the artificial limbs for those who need help.

INCREASING SOCIAL ACCEPTANCE OF DISABILITY

Ms. Sandy Heyman is changing public opinion about disability in South Africa. Here the disabled, like the different races, have been segregated--into separate schools and housed in large institutions. She, with other colleagues who are also disabled, organized and directs Public Awareness

of Disability Issues, a multiracial group of disabled persons who present educational programs to school children. Over 60,000 school students have attended a 2-hour program during which they experience disability through simulation activities and have an opportunity for questions and dialogue with disabled individuals. PADI is also teaching doctors, therapists, teachers and psychologists during their training as well as people currently working in the travel industry. They hire disabled people to be the teachers so that PADI provides employment at the same time it is changing attitudes. From a beginning in Johannesburg, it has grown to have branches in the Cape and Natal and the first rural team has been trained. Efforts to influence legislation are underway.

CHANGING AWARENESS OF THE POTENTIAL FOR IMPROVEMENT

Dr. Ashoka Pai is a psychiatrist trying to break the strong taboo against mental illness in India--taboo that causes families to hide people, fail to seek treatment or mistreat them. He is reaching the masses by the medium of television. He has personally produced the scripts and filming of four half-hour programs on manic-depression, mass hysteria, obsessive-compulsive behavior and extreme reaction to stress. He recruited a well-known screen star (and Fullbright Scholar) to direct the programs. The aims are threefold: (1) to educate the general populace about mental health problems, (2) to inform them that most problems are treatable and (3) to teach family members appropriate social treatment. These films have been made in Hindi to reach as many people as possible and will be shown on the National Network Television. Dr. Pai has had previous success using this medium for education about mental illness. He won the award for Best Art Film (in the local language of southern India) at a film festival. The film was subsequently aired on National Network Television. Breaking the taboos about mental illness in India is extremely important as there are many who are mentally ill or having temporary mental health problems. Many could be helpedif families would only seek medical care rather than regard the circumstance as hopeless, shameful and a hinderance.

DEMONSTRATING A MODEL FOR INTEGRATED EDUCATION IN URBAN AND RURAL SETTINGS

Mr. Prayat Punongong is demonstrating that integrated education for children who are blind is feasible in non-urban Thailand--practically, administratively and financially. Mainsteaming or integration for education, in every country I visited, is being discussed or is already public policy, but nowhere is it a reality. Education, to the extent it is available, is through special schools, often in a residential setting. There are many arguments for integrated education. Among them are that it allows children to remain living with their own family, to be as independent as possible in the community in which they must eventually live and to change stereotypic responses to disability by allowing non-disabled persons to learn and live with children who have a disability. Himself blind, Mr. Punongong did not attend school until age 15 because it was not available to him. Highly motivated, he has learned to speak English and is getting a master's degree. For integrated education to be successful, children must have (1) a means of learning and be able to get around and (2) regular classroom teachers who accept these differences and know how to cope with it. In northeast Thailand, Mr. Punongong has set up a special class for children who are blind. They attend

here for one year of intensive training that focuses exclusively on braille, mobility and independence in daily living skills (i.e., eating, dressing, toileting). Afterward, they are transferred into a regular class staffed by a teacher with some preparation for having a blind child in class. Recently, 80 regular classroom teachers who will receive these children next year attended such a short course.

INCREASING LEVELS OF EDUCATION

Despised and sometimes wasted in earlier times, girl babies have become prized in the past 20 years for the properous sex industry in Thailand. Statistics suggest that approximately 10% of attractive, young women enter, or are entered, into the lucrative and large prostitution trade. These girls can earn more in one day to support their families than the family members can collectively earn in a month. Most come from the poverty stricken areas of the north and northeast to Bangkok where the sex tourist trade is unofficially promoted by the government. Now AIDS is posing an enormous threat because many Thai men also use prostitutes. Economic predictions are grave. Despite being the #1 nation in the world in 1991 in gross national product, AIDS is expected to decimate the working population and return it to a low economic status. The number of babies born with AIDS is also increasing rapidly. **Apisuk Chantawipa** began working with prostitutes in 1984 to empower them--teach them English, health care (including use of condoms) and how to look out for themselves physically and financially. She formed EMPOWER (Education Means Protection of Women Engaged in Recreation) which is now an organization of 12 persons located in the Patpong area (known world-wide as "sin city"). They perform street plays in the area, have an office with information and counseling and a variety of programs to reach these young women on the streets. More recently, she began a program (Name of Life) which is for information and counseling of bar girls who have lost their ability to work because they are known to be HIV positive. Cambodia and Vietnam have a similar situation and are in dire need of programs to educate their prostitutes, especially about AIDS transmission. Many countries where prostitution is practiced less openly are also in need of model programs.

IN CONCLUSION

The stories of these men and women certainly support the ideals on which Ashoka is founded--that the actions of a single person can, indeed, make a difference and affect the lives of many people for the better. Each of these people is also a visionary and such a positive thinker that future projects are being conceiving long before the current one has been accomplished. There is no lack of good ideas and creative people to solve the problems humanity faces. What is needed is identification of such people, encouragement and facilitation, linkage and dissemination of information.

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WORLD REHABILITATION FUND, INC. AND THE UNIVERSITY OF NEW HAMPSHIRE
INTERNATIONAL EXCHANGE OF EXPERTS AND INFORMATION IN REHABILITATION

The Changing Face of Rehabilitation in Countries Around the World: Societal Attitudes and the Disability Movement

A Study Done in 1991-1992

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THE CHANGING FACE OF REHABILITATION IN COUNTRIES AROUND THE WORLD: SOCIETAL ATTITUDES AND THE DISABILITY MOVEMENT

Charlene Butler, Ed.D.

For ten months in 1991-1992, I traveled around the world to learn about the care of children with disabilities and to establish a network for the exchange of information among the professionals who are pioneering their care. I met many extraordinary people in 80 programs or governmental agencies and talked to well over 100 people in Greece, Turkey, Egypt, Kenya, South Africa, Seychelles, India, Nepal, Thailand, Singapore and Indonesia. They were their country's leading physicians, therapists and educators. One of my aims was to add to the data already being compiled by IEEIR concerning changes, if any, in societal attitudes and involvement in the disability movement. I conducted specific interviews to learn about the following:

- Ways people with disabilities are viewed and changes
- Ways availability of services have improved
- Personnel training and professional standards
- Roles of families, schools, churches and community organizations enabling greater participation in society
- How people with disabilities influence change
- Response to needs and resources of families
- How disability advocates can help in other countries

The information presented herein is not carefully researched, nor did I attempt to get a representative sample of opinion. Rather, it reflects information gleaned in interviews with 16 people and is bolstered by my general impressions from program site visits, discussions with many professionals, a few parents and disabled persons, perusal of disability newsletters and reports and just spending time in each country.

WAYS PEOPLE WITH DISABILITIES ARE VIEWED AND CHANGES

In every country, people spoke of how things had improved in the last ten years. This was attributed to the publicity generated for the Decade of the Disabled declared by the World Health Organization. During this period, information about disability and services appeared on television and radio and in other public media. Public education is believed to have raised the expectations that both physicians and families had about these "useless" children, i.e., that through treatment and education, they might become "useful" citizens. Consequently, there

has been an increasing flood of parents seeking services with requests greatly exceeding the services available.

During the decade of the Disabled, media coverage also sought to change societal attitudes. Simultaneously, a new philosophy of service delivery known as community-based rehabilitation was being introduced by the World Health Organization and foreign donor groups. In many cases, CBR programs met resistance from families and community members who did not want to accept these programs into community life.

Today, educated, upper class, urban-dwelling families seek services without fear of prejudice or social taboo. In villages and urban slums, however, pity and shame are still the strongest societal responses. This, plus the stigma of disability which disqualifies even siblings from marriage causes families to hid a person who is disabled. In Greece, this is true to the extent that some families forego government pensions to which they are entitled for their child's care. Even in more affluent and educated families, the desire to "get rid of" the child remains, and there is great demand for residential institutions. Though most programs are institutionally-based, the overall number is few, so most family members with a disability are reluctantly kept at home.

Belief in karma plays a significant part in societal acceptance of disability and treatment. In Buddahist and Hindu cultures, a person with a disability is seen as someone who must suffer in this life for deeds committed in a former life. The traditional belief is that one is born with one's karma; one neither can, nor should, try to change it. This belief is particularly strong in Nepal; it has diminished in Thailand and Singapore with increasing affluence and education in these countries.

Mainstreaming or inclusion in community life, as a concept, is being discussed or is already public policy everywhere I traveled, but exclusion and segregation into special schools and institutions is the reality. There is even recent civil rights legislation regarding employment and education of persons with disability in Turkey and Thailand. In Kenya and Indonesia, under the constitution, all citizens are entitled to equal social welfare conditions and jobs. No legal recourse is provided, however. Therefore, only those who can participate successfully in school or work with no special considerations are in the mainstream of society.

To date, treatment and education programs are separate and disability-specific. Day programs which allow children to live at home are available only in major cities; residential institutions are common and intended to serve children from rural areas. In the latter, disability

is generally regarded as a medical problem; this is reflected in most programs being organized and operated like hospital wards with nurses in attendance rather than like schools or group homes with teacher and parent figures. (An exception to this was the SOS Home for Disabled Children in Nepal.) Unfortunately, cerebral palsy and mental retardation are categorized under mental health services in many countries so that these children and adults are housed on the same campus with persons who have mental illnesses. The new Mental Health Act in India separated mental retardation from mental illness and reclassified it as a disability.

WAYS AVAILABILITY OF SERVICES HAVE IMPROVED

Though the legal and formal structures are improving, the money to implement programs in these countries is grossly inadequate. In each, a mushrooming population is overwhelming all infrastructures including schools, health programs and jobs. Despite the immensity of the economic and social problems this is creating and will continue to create as the population doubles in the next 32 years, the magnitude of services has grown and governments are lending support. Nevertheless, the number of persons needing service who get it is miniscule. Only guestimates can inform us about this percentage which is thought to be about 1-2%.

Services vary widely between countries. They hardly existed in Egypt despite its large population. There were only a few special education classes in government-funded schools for children who are blind or deaf. In the private sector, three small programs existed: two for children with mental retardation and one for children with multiple disabilities. Nepal, too, had a paucity of services, all instigated and managed by foreign donors and professionals. By comparison, South Africa and India had a plethora of services offered by national non-governmental social welfare organizations. Overall, my experience was that special education and physical therapy are practiced but are not widely available. Occupational and speech therapy are rare or non-existent.

Government-provided support is increasing. This most often takes the form of participation with non-governmental social welfare agencies. Social agencies establish and operate the programs; the government may provide, for example, a building or staff training. Governments are also soliciting or cooperating with foreign donors. In Indonesia, the government has officially adopted the community-based rehabilitation philosophy introduced by foreign organizations. It has established an infrastructure through a National Council of Social

Welfare (an indigenous, non-governmental agency) to extend CBR throughout the country. The Nepalese government has adopted a new constitution providing education for all and has formulated a national special education plan, in conjunction with a foreign donor organization which will fund it. Another way governments are supporting services is through public relations activities. The Turkish government advertises and promotes Special Olympics and the National Sports Federation for Disabled Games. The Indonesian government is talking about a media campaign to promote accessibility to the environment and to jobs.

Dedicated professionals and community leaders, often with the help of foreign donors, are responsible for most progams and are committed to better services for more people. Many services appeared for the first time during this last decade. In Nepal, no medical rehabilitation existed until the mid-1980's. Now there are two small hospitals with some outreach progams. Generally, medical programs have preceded educational ones. In Thailand, the number of children in educational programs doubled in recent years. Ten years ago, they were excluded from compulsory education. In Singapore, a school for children with multiple disabilities opened in 1987 with 40 children. Current enrollment is 250 with a waiting list of 150 children. Greece's first rehabitation hospital is on the drawing board. Turkey has its first public transportation bus with a ramp for riders in wheelchairs. The interdisciplinary team concept is being adopted by professionals in some areas, and subspecialty-trained physicians are being to appear.

Surprisingly, people who are well-off, financially and socially, fare least well. This includes the large ex-patriot populations often present. The private education and health care programs which serve them seldom provide for persons with disability. The schools, in particular, are exclusive and elitist; any child who has special needs will not be accepted or who fails or causes problems will be expelled. The only alternative for their families is to enroll them in overcrowded public programs which serve the lower classes. Special educators or therapists who might provide private therapy or tutoring are not available. These families often seek help abroad.

PERSONNEL TRAINING AND PROFESSIONAL STANDARDS

Manpower is a major problem. Though training programs exist for most types of professionals within their own countries, the number trained is insufficient. For example, India, with a relatively large number of medical schools, graduates only 125 physical therapists per year. Nepal and Seychelles must send all professionals abroad for training; and Singapore uses an affiliation in the United Kingdom to

train therapists. Professional standards for subspecialist physicians, therapists and special educators is a premature issue because the fields are new in all but South Africa and/or because there are insufficient numbers to form the societies that establish such standards. Continuing education is also not yet present.

Medical schools train physicians as specialists in orthopedics, neurology and pediatrics. Pediatric specialists or physicians knowledgable about the care of children with multiple disabilities are rare. Subspeciality training, e.g., pediatric orthopedics or developmental pediatrics, must be acquired abroad. In Greece, there is a small cadre of pediatric neurologists in the process of establishing a society. Professional standards for membership are being discussed. In India, I attended the ninth annual meeting of the National Neonatology Forum at which a topic of discussion was the need for professional standards.

Many medical schools also have a physical therapy training school. Occupational or speech therapy training is not available except in South Africa, although Egypt has physicians called phoniatricians who aid persons with hearing impairments. Physical therapy education focuses on traditional exercise programs.

Special education teacher training is quite new. In Greece, Turkey, South Africa, India and Indonesia, college level training is offered in at least one university usually leading to a diploma rather than a degree. No formal training exists in the other countries. General education teachers learn about special education on-the-job in most cases, even in countries which have some formal education.

ROLES OF FAMILIES, SCHOOLS, CHURCHES AND SOCIAL ORGANIZATIONS ENABLING GREATER PARTICIPATION IN SOCIETY

Participation in society is not an active concern of professionals, families or community organizations. It is a concept being promoted almost exclusively by external agents like the World Health Organization and foreign donors. It is being subscribed to by governments and individual programs mainly because foreign aid is dependent on acceptance of this philosophy.

HOW PEOPLE WITH DISABILITIES INFLUENCE CHANGE

There is little influence yet from this sector, but a few organizations of persons with disabilities are setting examples for effecting change. These have been the only internal agents urging greater participation in society.

No formal organizations have formed in Nepal, Seychelles, Singapore, Egypt or Kenya. There are some social beginnings, in Nepal, however, where there is a strong "club" of persons who are deaf. They responded to a request by a foreign donor to formulate a Nepalese sign language manual. A group of adults has formed for sports activities in the Seychelles. The Disabled People's Foundation is newly formed in Turkey; many of its members were participants in the Sports Federation for the Disabled Games.

Formally organized groups are individually working for change. The Association for the Physically Handicapped held a quiet demonstration in Jakarta, Indonesia to show how limiting the environment is. Afterward, they met with ministers to urge a government campaign to make new buildings accessible. An association with the same name mans telephone booths in cities in India providing jobs and demonstrating that they are contributing members of the society. The Self Help Association of Paraplegics in South Africa has set an example of organizing for employment in black townships and rural areas. People's Awareness of Disability is an organization of people with disabilities teaching about disability to change societal attitudes in South Africa through education of school children. Though initiated by an international organization whose mission is to promote self help, three voluntary agencies in India have established 84 groups with 1,120 members.

In Thailand and South Africa, local groups have formed a national coalition. Disabled People International in Thailand has had the most spectacular achievement. Theirs has been a ten-year effort to build acceptance within the government to create civil rights legislation. The Disabled Rehabilitation Bill (of Rights) passed last year.

Finally, families with political or economic power who have a personal experience with disability, make important contributions. The wife of the Greek Prime Minister (who herself had polio) spearheaded the development of a Rehabilitation Hospital for her country.

RESPONSE TO NEEDS AND RESOURCES OF FAMILIES

Family needs are not being addressed at any level in any country I visited. Families as a resource is manifested at the level of treatment in South Africa, India, Nepal and Indonesia where there are attempts to involve families in therapeutic exercises and some early education at home, but compliance is reportedly a problem. Non-compliance, in my experience, most often occurs when the "treatment" is not meaningful or relevant to families, i.e., it does not make a significant and observable difference in an areas they regard as important.

HOW DISABILITY ADVOCATES CAN HELP IN OTHER COUNTRIES

Disability advocates with an interest in assisting persons in other countries to recognize their rights need to do two things. (1) They need to clarify their own values and take care not to impose them on others. (2) They need to educate themselves about the circumstances in the country of interest and learn from the experiences of others. The following are comments that came out repeatedly.

There is no "disability movement" in developing countries as we know it. There is minimal concern about treatment and education in countries where, for many, life is a constant struggle to survive. A family member with a disability puts severe stress on their family, yet they do care for them. An understanding of the political, economic and social circumstances of the general populace is important in order to place what might be done in proper perspective.

There is considerable diversity within these countries: many and varied castes, cultures, religions, languages and traditions. Overlaying this, there are two systems defined by socioeconomic factors: the public system serving the general populace and the private serving the more affluent. A thorough understanding of all these aspects is critical to decide whether, how and who to "help".

Some of these countries have been the recipient of huge amounts of aid. A valuable source of knowledge is the experience of the many foreigners who have attempted to "help". There have been repeated and expensive disappointments due, in part, to westerners imposing their strong ideas about what they think should be done rather than assisting the people to accomplish what they want.

IN SUMMARY

Despite widespread and growing poverty, and severe shortages of housing, education, health care and employment, it was heartening to find so many fine, dedicated professionals committed to bettering the lives of persons with disability. Societal attitudes are changing to accept these members of society. Families do care and are seeking help. Governments are providing assistance--and even some funds which are exceedingly scarce. And people with disabilities are demonstrating, indeed, that they can not only be useful members of society but leaders.

PERSONS INTERVIEWED

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